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## Editorial

### **The European Association of Health Law: Addressing Unmet Needs in Policy, Practice and Research**

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#### **1. Introduction**

The European Association of Health Law (EAHL) held its Founding Conference at the Royal Society of Edinburgh in Edinburgh, Scotland on 10-11 April 2008. It was attended by over 100 delegates from 23 countries. During the conference, the Association's Constitution was approved and a Programme of Action agreed. This Editorial explains the history of the Association, its mission and objectives, the relationship with the European Journal of Health Law and the Association's plans for the future.

#### **2. The Establishment of an European Association of Health Law**

Initial steps towards establishing a European Association of Health Law were made during the 16th World Congress for Medical Law, held in Toulouse, France on 7-11 August 2006 and detailed in an earlier editorial in this journal.<sup>1</sup>

Associations of health law or health lawyers are not, now, new, and there are many national examples as well as numerous international organisations, perhaps most notably, the World Association of Medical Law.<sup>2</sup> What has not existed, however, is a body with the explicit remit of focusing on the contributions of *Europe*. This is defined in its broadest sense to include the range of countries making up the Council of Europe;<sup>3</sup> it is distinguished by the growing influence of its unique political and legal European Union;<sup>4</sup> and, arguably, it is characterised by its particular legal (and ethical) approach to human rights and human dignity as

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<sup>1</sup>) H Roscam Abbing, 'Founding a European Association for Health Law: the Rationale', *European Journal of Health Law*, 2006 (13), 203-207.

<sup>2</sup>) <http://www.waml.ws/home.asp>.

<sup>3</sup>) The Council of Europe currently has 47 member states, 1 applicant country (Belarus) and five observer countries (Canada, the Holy See, Japan, Mexico and the United States).

<sup>4</sup>) The European Union currently has 27 member states; Issues of expansion are addressed in the Treaty of Lisbon, but its future is in doubt at the time of writing after a referendum in Ireland to reject the Treaty.

embodied, inter alia, in the European Convention on Human Rights and more recent instruments such as the Council of Europe Convention on Human Rights and Biomedicine.

There can be little doubt that a European Association of Health Law will be sufficiently distinct from its national or global counterparts to add considerable value to what already exists. Henriette Roscam Abbing has pointed to a plethora of reasons that support the founding of a *European Association*.<sup>5</sup> A Regional Office of WHO for Europe was established early in the second half of the 20th Century, and the range of common concerns affecting European countries has increased considerably since then, from international activities to combat infectious diseases and promote public health, through to agreed health legislation programmes, the establishment of European courses on health law and the development and recognition of common patients' rights. The advent of the Common Market and the effect of principles of free movement of persons and services not only requires greater interaction between health care systems but necessitate closer approximation (or even harmonisation) of laws. Notwithstanding, the economic imperatives of a Single European Market brings their own challenges to the protection of patient rights and to the sustainability of 'traditional' European approaches to welfare and public systems of healthcare. As Roscam Abbing points out: "It is under such conditions that health lawyers must face the challenge of upholding equity in access to good quality health services, of avoiding a socio-economic divide, and of promoting patients' rights".<sup>6</sup>

An Advisory Board was created in 2006 to take forward the plans for a European Association.<sup>7</sup> It is a considerable undertaking to assume responsibility for establishing and operating such an Association across so many countries and for an indeterminate time. *Volonté* alone is not enough; there must be commitment to a clearly defined set of objectives and, just as importantly, recognition of the value of such an enterprise from potential funders who are willing to support the Association — at least in its initial stages — to build momentum around the intellectual and practical architecture that will be necessary to see the project through.

It was serendipitous, then, when Henriette Roscam Abbing approached me with the idea of founding the European Association of Health Law, that I was in a position not only to sign up to the project intellectually, but also to provide financial support under the auspices of *SCRIPT*, the law and technology Research Centre based in the School of Law at the University of Edinburgh of which I am

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<sup>5</sup> Note 1, above.

<sup>6</sup> *Ibid.*, at 206.

<sup>7</sup> Members of the advisory board are: Maria Bottis (GR), Anne-Marie Duguet (FR), Jos Dute (NL), Lars Falberg (SE), Sjeff Gevers (NL), Dieter Hart (DE), Bernard Koch (DE), Graeme Laurie (UK), Salla Lötjönen (FI), Geneviève Pinet (WHO), Henriette Roscam Abbing (NL), Elisabeth Rynning (SE), Judith Sandor (HU), Maria Sokalska (PL), Dominique Sprumont (CH) and Asim Sheikh (IE).

the Director.<sup>8</sup> *SCRIPT* is funded by the United Kingdom's Arts and Humanities Research Council which supports high-quality research and capacity building across the entire range of the arts and humanities, with a particular focus on inter-disciplinarity and knowledge transfer.<sup>9</sup> A particular interest of our Centre lies with health-related technologies, and health care provision more generally. The advent of an Association of European Health Law perfectly complemented our objectives, and most particularly, our commitment to our funders to position the Centre as a body contributing directly to the formation of law and technology policies and legal and regulatory responses to advances in science, technology and medicine.

To move the initiative forward, an initial meeting of a Steering Committee, drawn from the Advisory Board, was held in Toulouse, France, in July 2007. At this meeting, the decision was taken to hold a Founding Conference in Edinburgh, Scotland, in 2008. The conference would be an opportunity to discuss and agree the Association's Constitution, its Mission and objectives, its membership, and its programme for future action. What follows is an account of that meeting and its outcomes.

### **3. The Founding Conference of the European Association of Health Law**

The Founding Conference of the Association took place on 10th and 11th April 2008 in the Royal Society of Edinburgh, Edinburgh, Scotland. It was attended by over 100 delegates from 23 countries. The programme and list of speakers can be found at the Association's website.<sup>10</sup> The format of the meeting involved plenary and break-out sessions to allow delegates both to engage with some of the more controversial topics facing health lawyers in Europe today, and also to consider the proposals put by the Steering Committee on the operation and Constitution of the Association itself. It was suggested and agreed that the Association should be particularly keen to encourage young scholars, and to this end the conference included a poster competition at which contributors were encouraged to present a poster on their work and to engage with delegates on the substantive issues. 15 posters were presented and a free vote was held over the two days of the conference on the best entry. The winner was announced as Thomas Goffin of Leuven University.

Several of the papers presented at the Founding Conference appear in this issue. Day 1 was launched with a Keynote Address from Sjef Gevers, who gave a masterly overview of health law in its historical and contemporary European

<sup>8</sup>) <http://www.law.ed.ac.uk/ahrc>.

<sup>9</sup>) <http://www.ahrc.ac.uk> Our Centre seeks direct collaborations in and beyond the legal academy towards policy and practice-driven ends. Its role is to serve as an international research hub with a clear focus on creating and developing new legal responses to the demands and potentials of new technologies.

<sup>10</sup>) <http://www.law.ed.ac.uk/ahrc/eahl>.

contexts, highlighting some of the key future challenges for the Association and its members. Following sessions then considered how the Association might best pursue its core purposes in the fields of Networks & Funding (Anne-Marie Duguet and David Townend) and Teaching & Training (Marleen Eijkholt), and these were accompanied by break-out sessions to garner input from delegates. Institutional perspectives were then offered in a plenary session by Nicola Robinson (European Commission) and Tina Garanis-Papadatos (Council of Europe), both of whom welcomed the launch of the Association as a valuable initiative. The first day was closed with papers by Roberto Andorno and Herman Nys on international dimensions of European health law to give a broader perspective on the future work of the Association.

The focus of Day 2 was on research and horizon-gazing as two core objectives of the Association. It involved a series of academic papers on *What is the Future of Health Law in Europe?* The Keynote Address was given by Tomas Poledna, who offered the example of recent economically-driven changes in Swiss health insurance to highlight some of the tensions and challenges for European public welfare systems as they face growing costs and demands in health care. This theme was continued by Elizabeth Rynning who considered ageing populations and the implications for the notion of the European Welfare State. Maria Bottis then addressed one of the enduring common concerns in European health law, viz, protection of medical data. The theme of ethnic and cultural diversity was taken up by Aart Hendriks, who focussed on marginalised groups and the threat of discrimination around Europe, while Ergun Özsunay offered valuable comparative insight from a Turkish perspective on key medico-legal issues. The final academic sessions were concerned with future challenges, for both medicine and law, with Maja Grymzkovska and Guilherme De Oliveira considering issues of preventative medicine, and Dominique Sprumont and Roger Brownsword addressing the role of regulation in medical research; they each suggested, in their own way, that we should be careful not to expect too much of law lest it become a burden or hindrance to the achievement of valuable social and health-related ends.

#### **4. What Can We Expect of the European Association of Health Law?**

The conference was also an occasion to discuss the Association's Constitution and its *modus operandi*. The organisational structure of the Association, including its Constitution (which was approved at the conference), can be found at the Association's website.<sup>11</sup> The following was agreed with respect to the philosophy, objectives and future action of the EAHL.

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<sup>11</sup>) <http://www.law.ed.ac.uk/ahrc/eahl>.

#### 4.1. *Identifying Unmet Needs in the European Health Law Context*

After plenary presentations on Networks & Funding and Teaching & Training, delegates split up into break-out sessions to identify the added value that could come from the European Association. It was universally agreed, for example, that there would be considerable value in a central database to identify members, their interests and affiliations, to highlight health law centres across Europe, to raise awareness of publications and on-going projects, and to share teaching resources and other materials. This database should be used towards multiple ends, including facilitating connections between members, establishing and maintaining networks, capacity building, creating knowledge repositories, for example, of laws, law reform measures and research projects, and as a means to learn from and consolidate experiences across Europe.

The added value of the Association in terms of networks and funding could lie both in the realms of contributing to existing networks as well as establishing new networks under the auspices of the Association itself. It was agreed that the Association should perform an important scoping function with respect to calls for funding on health law-related projects, and it could further perform a coordinating function in facilitating groups of members to come together to respond to such calls or simply to provide members with an opportunity for on-going interaction along thematic lines to build a shared knowledge base. Such functions would also raise the profile of the Association, its networks and members to enable persons seeking information and advice on (European) health law and to identify core areas of expertise. Mobility of members around Europe could be facilitated through bids to funds such as the Marie Curie Foundation, and it would be valuable too to raise awareness of doctoral studentships or other opportunities around the Association's constituency. The possibility was also mooted of establishing an independent Foundation with its own funds which might, on an agreed basis, attempt to influence agenda in the setting of health care policies around Europe.

In the realm of teaching and training it became apparent quickly that there was a range of unmet needs around Europe. This was true among health lawyers themselves — and especially in Eastern Europe — in terms of gaining access to quality materials and having deeper understandings of comparative methodologies for teaching health law; and it was true also with respect to wider audiences who might require training on health law, including health professionals, policy makers, politicians, and many other sectors of the European public. The Association could therefore play an important role in sharing good practice and materials, facilitating the development of model curricula or health law options that could be adapted to local needs, helping to establish courses where there are none, and developing comparative courses to encourage mutual learning and recognition around Europe. While mobility of students and teachers around the region was thought to be valuable, the Association could also take full advantage of

technological developments to promote wider dissemination of knowledge through the use of distance learning, virtual classrooms and the sharing of electronic materials.

In order to realise these aspirations for the European Association of Health Law it is important to be clear about its Mission and objectives, as well as what members and other can expect from the Association. To this end, the following matters were endorsed at the Founding Conference.

The *Mission Statement* of the EAHL is:

The European Association of Health Law aims to strengthen the health and human rights interface throughout Europe, and to serve as an indispensable source of advice and guidance for the future of health law and policies in Europe.

The *guiding principle* of the European Association of Health Law is the achievement of academic excellence and the improvement of health law practice. Its *overarching purpose* is to bring together health lawyers from around the Council of Europe to discuss and collaborate on issues of importance in the development of health law and policies.

#### 4.2. *Principal Objectives*

The principal objectives of the Association are:

- To promote health law research, teaching and practice throughout Europe;
- To encourage and facilitate co-operation in these areas among health lawyers throughout Europe;
- To encourage and support the development of health law in European and international relations;
- To engage pro-actively in discussion on topical issues of health law and to assess and respond to new and emerging challenges for health law;
- To promote a greater awareness and understanding of health law nationally and in the European context.

#### 4.3. *Instruments*

The Association will achieve its objectives by:

- Providing opportunities and fora for discussions, academic and practical exchanges, expert communications and public engagement on contemporary issues in health law;
- Encouraging EAHL-sponsored research networks in specific fields of health law;

- Organising and supporting conferences, workshops, symposia and training courses;
- Facilitating events and networks to encourage young scholars in their work;
- Issuing opinions and giving advice on matters of common European interest;
- Promoting quality publications for a wide range of audiences with an interest in health law and health law-related issues;
- Advancing teaching and training in these areas;
- Providing a Health Law Coordination Function (i.e., with respect to publications, research, teaching programmes and courses, contacts and databases; perhaps best achieved via a web-based database).

#### 4.4. *Network Support*

The EAHL is committed to encouraging EAHL-sponsored networks. To this end, members involved in an EAHL-sponsored network will receive specific support from the EAHL for their network. This will include:

- Identification and contact of potential collaborating partners
- Assistance in the formalisation of the network
- Assistance in the construction of an appropriate model for the network
- Establishment of EAHL-supported interest groups to bring interested parties together for further discussion and collaboration on subjects of mutual interest
- Advice and support in making funding applications and seeking sponsorship.

#### 4.5. *European Journal of Health Law*

Finally, and as a measure of support for the Association and its members, new members of the Association will benefit from a 50% reduction in subscriptions to the *European Journal of Health Law*.

### **5. What is the Future Programme of Action of the European Association of Health Law?**

#### 5.1. *Working Groups*

Consensus emerged at the conference that it would be important to establish three Working Groups to drive the work and the contributions of the Association forward and to maximise its impact across a range of possible fields. Each group will report on its activities at the bi-annual conference. The three Working Groups are:



Working Group 1: Networks and Funding (contact: Anne-Marie Duguet)<sup>12</sup>

The objective of this Working Group is to facilitate formal and informal networks of members and other interested parties for research and other research-related activities, as well as to help in the coordination of funding bids, either among members, new or existing networks, or for the Association itself.

Working Group 2: Teaching and Training (contact: Graeme Laurie)<sup>13</sup>

The objective of this Working Group is the improvement of health law teaching and training across Europe, through exchanges of best practice and experience, cross-fertilisation of ideas and the maximisation of dissemination opportunities. A particular area of unmet need that emerged during the conference was capacity building and training in Eastern European countries.

Working Group 3: Institutions (contact: Herman Nys)<sup>14</sup>

The objective of this Working Group is to maintain a watching brief on European and international institutions whose work has a direct impact on health law and policy and where input from the Association might have a significant role to play. Obvious examples are the European Commission, the Council of Europe and the World Health Organisation.

Anyone who is interested in being directly involved in the Working Groups is invited to get in touch with the relevant contact person.

## 5.2. *The Voices of the Association*

Henriette Roscam Abbing has rightly pointed out that: "The success of this undertaking depends entirely on the voluntary assistance and support of health lawyers throughout Europe".<sup>15</sup> This means not only that individuals should join as members and actively participate in the work of the Association (see further below), but it may require that particular individuals within countries take on a coordination and liaison role with members in that country and the Association. We would welcome comments and volunteers in that regard.

As for the Association itself, it may be an appropriate and realisable ambition to seek representation in due course within international organisations which deal with matters of health law and policy. The European Commission is taking an increased interest in health law, see for example, the recent proposal for a Directive on the application of patients' rights in cross-border healthcare,<sup>16</sup> while the Council of Europe's Convention on Human Rights and Biomedicine has

<sup>12)</sup> aduguet@club-internet.fr.

<sup>13)</sup> graeme.laurie@ed.ac.uk.

<sup>14)</sup> Herman.nys@med.kulueven.be.

<sup>15)</sup> Note 1, above, p.207.

<sup>16)</sup> EC, Proposal for a Directive on the application of patients' rights in cross-border healthcare, COM (2008) 414 final, 2 July 2008.

spawned numerous protocols since its inception and will doubtless produce more in the future. Moreover, the Association can have a central role to play even when law is not the central issue, and numerous examples come to mind, including contributing to the ambitious plans of the European Commission to accelerate the e-health market within the next few years,<sup>17</sup> and giving effect to the provisions of the Council of Europe's Bratislava Declaration on health, human rights and migration.<sup>18</sup> These and other matters are for further discussion and debate in the official forum of the Association, which will be its Bi-Annual Conference.

### 5.3. *Bi-Annual Conference*

Delegates were confident about the complementarity of the European Association of Health Law to national and international bodies and of the considerable added value that a European Association will bring. A bi-annual conference will be necessary to provide an opportunity to bring the General Assembly together, to assess progress and to agree future objectives. By the same token, the Association must be aware of the work of other bodies to avoid duplication of effort and to ensure that the *European Association* optimises its contributions where possible. To this end it has been agreed that the bi-annual conferences of the EAHL should take place in alternate years to the World Association for Medical Law, and that in the first instance this will require the Second EAHL conference to take place in 2009. I am delighted to announce that it was furthermore agreed that this meeting should take place, once again, in Edinburgh, and I invite you all to join us at the Royal College of Physicians, Edinburgh, Scotland, on 15th-16th October 2009.

**Details of membership of the European Association of Health Law, and of the 2009 European Association of Health Law conference appear on the Association website: <http://www.law.ed.ac.uk/ahrc/eahl>.**

GRAEME LAURIE

*Professor of Medical Jurisprudence*

*Director, AHRC/SCRIPT Research Centre, School of Law, University of Edinburgh*

*Graeme.Laurie@ed.ac.uk*

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<sup>17</sup>) European Commission, Accelerating the development of the e-health market in Europe, 2007.

<sup>18</sup>) Council of Europe, Bratislava Declaration on Health, Human Rights and Migration, 23 November 2007.

